

Russell Nittler

From: Finn Bullers <fbullers@icloud.com>
Sent: Tuesday, October 22, 2013 1:08 AM
To: Russell Nittler
Subject: Fwd: Tuesday, Oct. 22, 2013 | KanCare concerns to be distributed to two working groups, Russell Nittler | Finn Bullers

From: Finn Bullers <fbullers@icloud.com>
Date: October 21, 2013, 10:22:51 PM CDT
To: KanCare <KanCare@kdheks.gov>
Cc: Alice Christiansen <grtn@myclearwave.net>, Alice Diane Bullers <adbullers@gmail.com>, tom.bullers@gmail.com
Subject: Tuesday, Oct. 22, 2013 | KanCare concerns to be distributed to two working groups, Russell Nittler | Finn Bullers

Tuesday, Oct. 22, 2013



Mr. Russell Nittler
Kansas Department of Health & Environment
KanCare@kdheks.gov
(785) 296-4885

Dear Mr. Nittler --

Greetings from Prairie Village, Kansas.

My name is Finn Bullers and I am a 49-year-old father of two who is embroiled in a fight with the state of Kansas over the reduction in my care hours from full time care to 40 hours a week.

I appreciated talking with you Monday afternoon and the time you took to listen to my concerns. I am grateful that you will pass on my comments below and my contact information to the two KanCare working groups.

For everyone involved, that may prove to be the most effective way to distribute my message than the time-consuming process of filing an information request for the names and contact information of members of the two working groups allowed under the Kansas Open Records

Act.

I believe KanCare practices push abled-minded clients out of their homes where they are receiving care and in to institutional settings -- a violation of the Olmstead Act, Title II under the Americans with Disabilities Act.

A good friend of mine, Gary Blumenthal with the President's Council on Disability, suggested I contact your office to apprise you of how the state of Kansas is proceeding to cut the care hours provided to me and 379,999 other Kansans with disabilities.

But in my opinion, this case takes on added significance given the pilot-project nature of the state's new managed-care program run by three private insurance companies and their bottom-line politics motivated solely by money.

For if the MCOs are deemed a "success" here in Kansas, the model will be imported across the nation. That would be an unfortunate and tragic mistake.

I have a rare form of the muscle-wasting muscular dystrophy. I am also a 35-year, type-one diabetic and use a ventilator to breathe. My doctors say it is critical that I receive full-time care to stay alive. The state wants to cut my hours to 40 hours a week.

Gov. Sam Brownback and his new privatized, managed-care Medicaid program, known as KanCare, have said that I only need the 40 hours of care to live. They refuse to discuss why they have reached that conclusion and upon what criteria they made that decision.

In Kansas, the profit-motivated insurance industry is calling the shots on who gets what care based on bottom-line motivators -- not a patient's medical needs.

If the reduction in care hours comes to pass, my wife and I will be forced to file for divorce or even bankruptcy. That is the only way we can even try to remain financially solvent.

The state says that it is implementing the reduction in care hours to cut costs, while at the same time "improving outcomes."

But are divorce and bankruptcy "improved" outcomes?

The GOP plan is designed to cut \$1 billion over the next five years and make KanCare more efficient and provide better care for Kansas with disabilities.

This claim is patently offensive on many fronts. In my opinion it violates the Olmstead Act, Title II under the ADA.

The more I read the ADA and Olmstead, the more I begin to question how the state KanCare policy can legally be upheld. The way I read Olmstead, it is an ADA violation to force an otherwise able-minded person into institutional settings. Yet that is exactly what the outcome of Kansas policy begets.

I am in the early stages of doing some research, but it appears to me as if the go-to option for KanCare officials is to push the institutional housing model before exhausting all other options.

Interesting to note is the fact that nursing home admittance numbers are significantly higher in

the Sunflower State then it is any surrounding Midwestern state including Illinois, Nebraska, Iowa and others. I question why that is the case.

The only answer, it seems to me, is the fact that state policy is skewed toward making nursing-home admittance a first and foremost option rather than the last option available to a client. It is also interesting to note that many KanCare regulators are former nursing-home leaders or are otherwise tied to institutional health care.

Under KanCare, the goal of Kansas Gov. Sam Brownback is to cut that \$1 billion to the state's most vulnerable in an effort to curry favor with the ultra-right wing faction of the GOP to propel him to the presidency in 2016.

Shawn Sullivan, Secretary of the Kansas Department of Aging and Disability Services, said in several interviews that he personally approved my cuts in care hours from full-time to 40 hours a week -- a 76 percent drop. He said the cuts are completely appropriate, but refuses to say why.

"There is just no doubt that you are in their sites," one consumer advocate told me via email after attending the meeting.

For years, Kansas regulators -- and officials in other managed-care states -- have felt their former care systems were being abused by those who did not deserve to receive disability benefits. And that indeed may be true.

But in my case, the burden of proof lies with the state to prove that the former system was so irretrievably broken that a drastic rush to judgment overhaul was necessary -- without the due diligence in place to avoid such catastrophic outcomes for me and nearly 400,000 other Kansans with disabilities.

As we have seen on a recent "60 minutes" segment -- "Disability USA" -- there is indeed widespread examples of national social benefit fraud.

But the state of Kansas has simply put the bullseye on the back of the wrong target -- one hardworking, play-by-the-rules Midwesterner with his nose to the grindstone and his eyes on the future of his two children

Systemic cases of fraud should be the state of Kansas' prime target -- not a 49-year-old father of two just striving to take another breath and live to watch his children go on their first date -- or even graduate high school.

In several media accounts and personal contact with top state officials responsible for disability issues, there is a group-think message delivered off the same sheet of talking points: "I'm sorry, Mr. Bullers, but this is our policy. We can not discuss the details of the case, but we feel comfortable with the reduction of hours."

However, it is the details of my case that justifies the needed level of care my doctors all agree upon. And it is the details of the case that Kansas power brokers choose to ignore.

Consider just some examples:

My new, reduced-hours plan of care approved personally by Sec. Sullivan justifies leaving me unattended by stating I have a ramp to wheel outside my home -- if I can even manipulate a door

without the use of my neurologically useless hands.

And to do what? Knock on a neighbor's door three steps up that I can't access in a working-class neighborhood where both adults work full-time and are not home for up to 12 hours a day?

The care plan also indicates I can use my cell phone to call 911 in case of an emergency, say if my breathing tube was to become detached, which can, and does happen on occasion. In that scenario, no air is pushed by the ventilator breathing machine into my lungs and across my vocal cords, rendering me unable to speak.

How can I then place a 911 call? And even if emergency responders could triangulate the call through GPS technology to pinpoint my location, even lightning-speed paramedics could not reach me in time before I ran out of air.

And died.

The state's new care plan also gives me approximately six minutes to eat dinner, a traditional family bonding period where issues of the day are discussed and upcoming plans and individual responsibilities are doled out.

I am given two minutes a day for complete oral hygiene and an hour block to toilet only during specified hours allotted by the state. I have tried many times to reduce my liquid intake (something my doctors strongly discourage) and regulate my body function to such ascribed time frames. But as has been said, "When ya gotta go, you gotta go."

I certainly hope my need to defecate when necessary is not what Sec. Sullivan defines as abuse of the state's Medicaid system.

Asking state of Kansas health-care regulators to re-examine the details of my plan for the inconsistencies described above is tantamount to trying to reason with a totalitarian state. They simply refuse to reason.

The message: State government has forgotten that government is the rule of the regular citizen and derives its power from the people they are elected by -- and represent.

For nearly 50 years, my Midwestern life has always been a nose-to-the-grindstone affair fueled by a solid work ethic and an obligation to contribute.

Now, however, I find myself on the receiving end of social benefits that many in Kansas feel the disabled do not deserve. But I am not asking to get rich, I am only asking to survive, provide for my family and be given an equal opportunity to compete on a level playing field.

That is not only my dream, but the shared aspiration of my United Spinal Association colleagues in the global disability community.

My team of doctors all concur that my high level of care is absolutely necessary to keep me alive.

That, however, does not sit well with the bean counters at the state's three managed-care organizations, or MCOs, run by mega insurance companies -- UnitedHealthcare, Amerigroup and Sunflower.

Calling the shots are administrative folks like Sec. Sullivan who have no medical training to make such drastic cuts based on an inefficient health-care bureaucracy the state helped to create in the first place.

I'm asking the state of Kansas to respectfully remove the Medicaid fraud target on my back that has put me in the crosshairs of state regulators and decisionmakers who are aiming powerful and life-threatening weapons in the wrong direction.

Some thoughts from last Monday's meeting:

-- From my perspective, it seems that the 11-member oversight committee needs to address the definition of what it means to be a KanCare ombudsman. After Mr. Bart's testimony on Monday, it became clear to me why many of my attempted efforts to reach the office had been unsuccessful -- until I took the more drastic approach to email the governor directly.

In my world, the term ombudsman has always been synonymous with advocacy efforts on behalf of a certain population. And the role of traffic cop for information was merely a functionary process of administrative staff. Is the state willing to provide a more active role for an ombudsman, or perhaps an outside group could fund that watchdog advocacy role of an internal auditor type position to advocate for KanCare recipients and be a KanCare watchdog -- without having to derive a check from the very people they are designed to oversee.

-- Data collection: Much of the data that was presented by KanCare advocates at Monday's meeting seemed to lack context to provide residents an understanding of what the numbers actually mean. There was a big number and a percentage but no comparison to national standards or nearby state statistics to be used as a benchmark so readers could be comfortable that KanCare is headed in the right direction.

-- It was also disturbing to see data collection regarding the number of phone calls received by Mr. Bart in the ombudsman office. Out of more than 1,300 calls, some 870 calls were defined as "unspecified," even though, under questioning, it was clear one unspecified call clearly identified the needs for a past-due wheelchair.

-- Ombudsman staff: Mr. Bart is a one-man show responsible for serving the needs of 380,000 Kansans who receive Medicaid services. By contrast, ombudsman employees in Wisconsin have a work load equivalent to one caseworker for every 3, 800 clients.

Last Friday, Matt Keenan with Shook Hardy & Bacon, Kansas City's largest law firm, said their court-ordered, child-in-need-of-care caseload already is too full and said he could not justify diverting his firm's child-focused pro bono resources to my case.

However, Tim Wood of the Disability Rights Center of Kansas said his organization supports my efforts to challenge KanCare's reduction in my care hours and said he is willing to throw his organization's limited resources behind the fight. You can chat with Wood on his cell phone: (785) 409-5827.

I have written about my case in my "Squeaky Wheel" blog at the United Spinal Association, a 44,000-member organization found in 44 states --- www.usersfirst.org

My case has garnered some media attention:

-- <http://www.kansas.com/2013/10/07/3045665/kancare-system-criticized-in-topeka.html>
-- <http://www.khi.org/news/2013/oct/07/kansas-medicaid-providers-complain-oversight-commi/>
-- <http://www.khi.org/news/2013/oct/07/prairie-village-man-fighting-kancare-service-reduc/>
-- <http://fox4kc.com/2013/10/08/planned-kancare-cuts-have-some-with-disabilities-scrambling-for-contingencies/>
-- <http://pvpost.com/2013/10/08/prairie-village-man-testifies-about-troubles-with-kancare-21877>
-- <http://viewfromthemidwest.com/2013/10/10/opinion-letter-writing-campaign-targets-kancare-ruling/>
-- <http://viewfromthemidwest.com/2013/10/10/prairie-village-man-fighting-kancare-service-reduction/>
-- <http://www.kshb.com/dpp/news/health/prairie-village-man-upset-after-kancare-cuts-back-his-personal-coverage#ixzz2hxKpDOcf>

I am asking you to please take a look at my case and see if there are any resources that you and your team could provide me in helping to battle my case with the state. I have filed an appeal and my case is now under way.

Thank you so much for considering my case. I appreciate all your effort and good work.



Warm regards, Finn Bullers

Freelance writer/editor -- stuff media
Advocate for people with disabilities
Former reporter for The Kansas City Star
Age: 49; wife, Anne, and two children: Christian, 13; Alora, 9

3515 W. 78th St.
Prairie Village, Kan. 66208

H: 913. 649. 6693
C: 913. 706. 2894

Finn.bullers@aol.com

Finn M. Bullers, 49, of Prairie Village, is a freelance writer/editor who has spent the last 28 years as a professional journalist from Miami to Bismarck, N.D., but centered mainly in the Midwest, reporting for 15 years as a political and suburban affairs reporter for The Kansas City Star.

Bullers, who has hereditary muscular dystrophy and is a 35-year Type-1 diabetic, uses a power wheelchair and a ventilator to breathe. He works as a national advocate for people with disabilities and writes a column for the United Spinal Association, advises an elementary school newspaper and lives in a brown ranch home on a cul-de-sac, with a ramp van, his wife and two children.